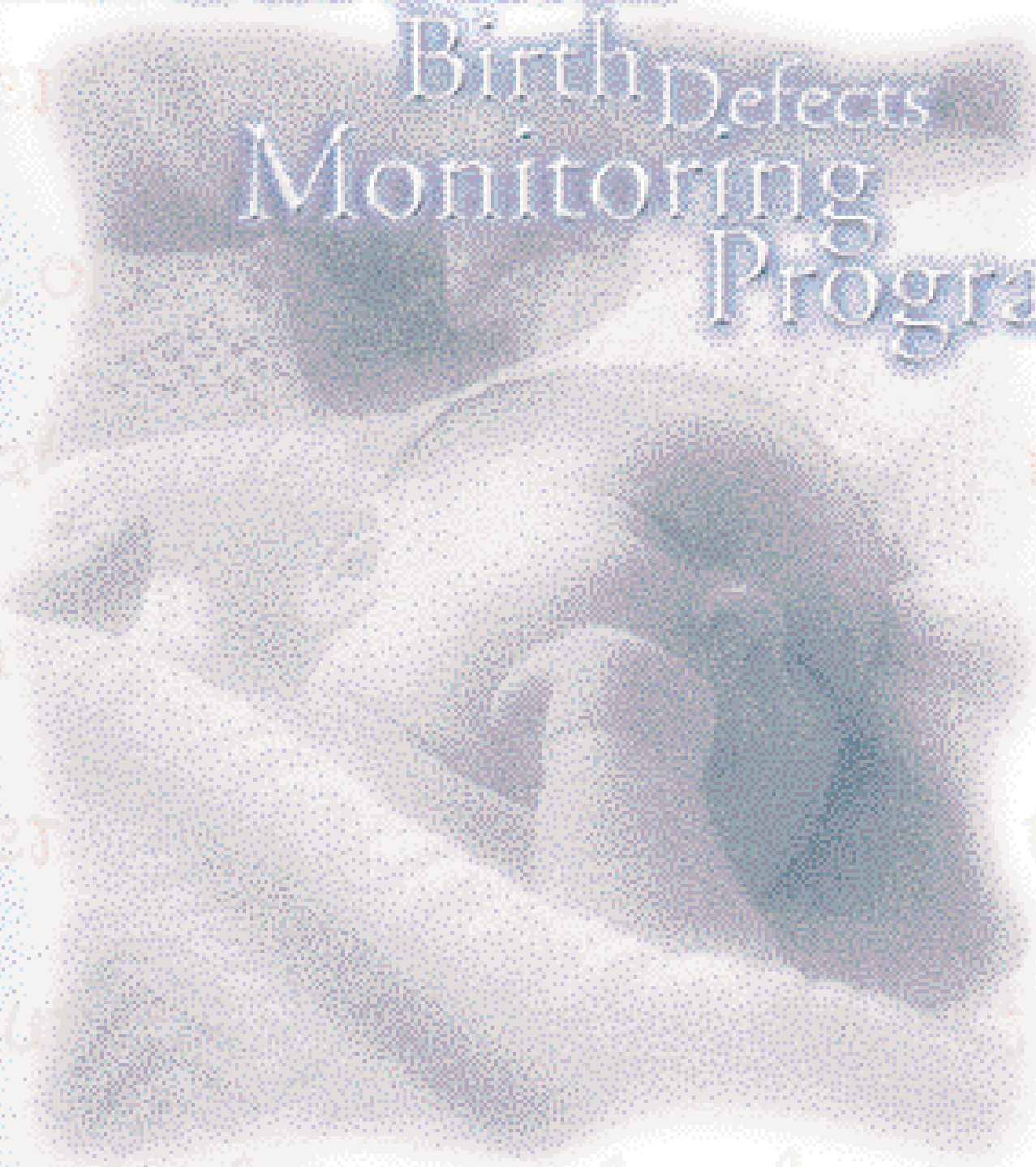
North Carolina Birth Defects Monitoring Program



Surveillance Report • July 2000

North Carolina Birth Defects Monitoring Program

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March of Dimes

Table of Contents

Birth Defects in North Carolina

A birth defect, as defined by the March of Dimes, is an abnormality of structure, function, or body metabolism that is present at birth and results in physical or mental disability; birth defects can also be fatal.[1] The cause of many of these conditions is unknown, though some birth defects have been linked to genetic factors, maternal illnesses, and environmental influences. Each year in North Carolina more than 3000 infants, or about one in every 30, are born with serious birth defects. The number increases substantially when miscarriages, stillbirths, and pregnancy terminations are considered.

It is certainly possible for individuals with birth defects to live full and enjoyable lives, but many require substantial medical care that can create serious economic hardships. In-patient hospital care alone for affected children age 18 and under in North Carolina is $117 million per year, accounting for approximately 20 percent of the total hospital charges for children in this age group. The average charge per hospital admission for children with birth defects is $14,000, higher than the cost of any other pediatric medical condition.

This report is designed to provide information concerning birth defects in North Carolina, particularly neural tube defects, orofacial clefts, cardiovascular defects, and chromosomal disorders. These conditions represent nearly 40 percent of all serious birth defects in the state (Figure 1).

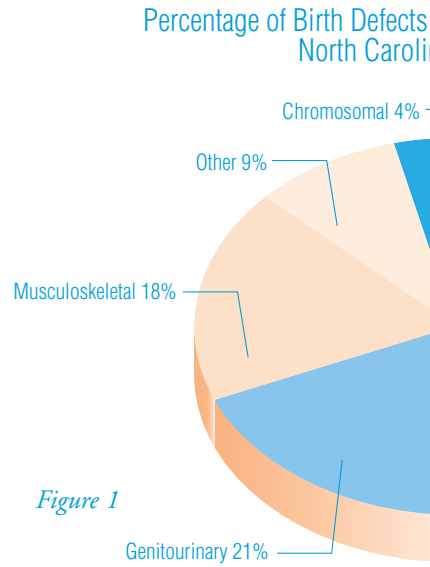


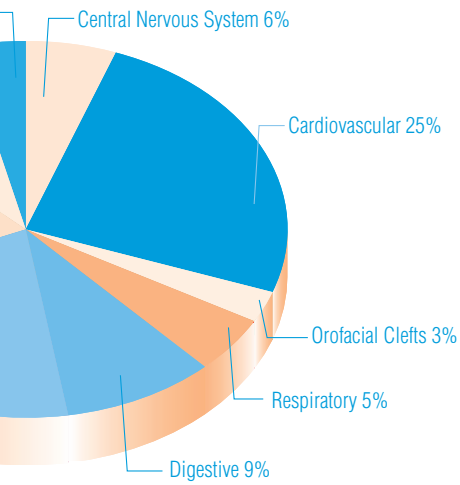
Figure 1

North Carolina Birth Defects Monitoring Program

Improving the health status of infants and children in North Carolina is the primary goal of the North Carolina Birth Defects Monitoring Program (NCBDMP). Specifically, the NCBDMP aims to:

- Help individuals and families with birth defects locate resources for economic and emotional support
- Identify causal factors of birth defects, pre-term births, and other adverse pregnancy outcomes
- Educate health care providers, researchers, and the public about preventing birth defects
- Recognize who is at an increased risk for having a baby with a birth defect
- Help decrease the incidence of birth defects, low birthweight, and prematurity in North Carolina

Diagnoses by Organ System,
na, 1995-1997



North Carolina began monitoring birth defects in 1987. Data were obtained using a passive surveillance approach, in which information from vital records (live birth, fetal death, and infant death certificates), hospital discharge reports, and other sources were collected in order to provide information about birth defects. In 1995, the North Carolina General Assembly passed legislation intended to improve the monitoring program. This legislation allowed trained NCBDMP staff to access and review hospital medical records and discharge reports to ensure more complete, accurate, and timely information (active surveillance). This method of data collection was initiated in 1997. Funding for the NCBDMP is provided by State appropriations, the March of Dimes, and the Centers for Disease Control and Prevention (CDC).

All personal identifying information collected and maintained by the NCBDMP is considered confidential. Published data are presented at an aggregate level in order to protect patient confidentiality. The NCBDMP also provides other reports and statistical summaries upon request; readers needing further information should contact the State Center for Health Statistics.

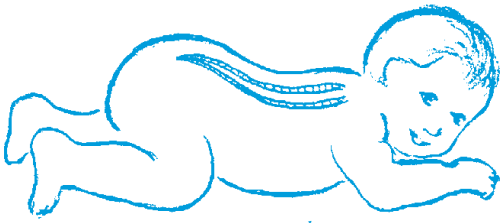
Neural Tube Defects

A neural tube defect (NTD) is a type of birth defect in which the structure that forms the brain and spinal cord (i.e., neural tube) fails to develop properly during the first four weeks of pregnancy. A defect in the neural tube usually results in some degree of physical and neurological impairment. The two main types of NTDs are anencephaly and spina bifida, which comprise nearly 80 percent of all NTD cases.

Anencephaly occurs when the cranial portion of the neural tube fails to close, resulting in incomplete development of the brain. Infants with anencephaly are unable to survive outside of the womb. They are either stillborn or die shortly after birth.

Spina bifida occurs when the neural tube fails to close along a portion of the spine, leaving the spinal cord and its membranes exposed (Figures 2-4). The opening must be surgically repaired. Individuals with spina bifida often have associated conditions such as hydrocephaly ("water on the brain"), clubfoot, mental retardation, muscle weakness/paralysis, loss of bladder and bowel control, as well as other complications.

In North Carolina, approximately four pregnancies are affected each week by an NTD (nearly 200 cases/year), with only half resulting in live births. These defects occur more often in North Carolina and other southeastern states than elsewhere in

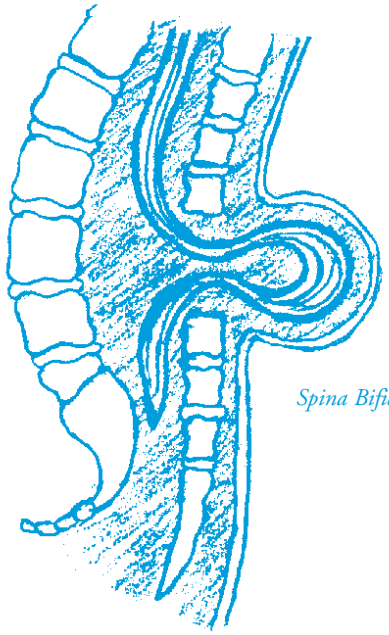


normal

Figure 2

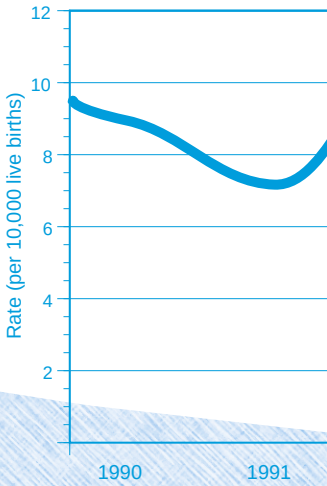
Spina Bifida

Figure 3



Spina Bifida, detail

Figure 4



the United States. The reasons for this disparity are not known. Within North Carolina, NTD prevalence is higher in the western perinatal region of the state (Figure 5). There has been no consistent trend in NTD rates since 1990 (Figure 6). Women under age 25 and over age 34 have higher rates of NTD-affected pregnancies than women in other age groups (Figure 7). One possible explanation for the higher rates seen in young women is that they are less likely to take a multivitamin containing folic acid.

Numerous studies have shown that the intake of folic acid decreases a woman's risk for having a pregnancy affected with an NTD by up to 70 percent.[2-5] Women should take a daily multivitamin containing 400 micrograms of folic acid **in addition** to eating a healthy diet.[6] In order for this vitamin to be effective, it is important that women of childbearing age consume this amount of folic acid at least two months prior to conception and throughout pregnancy.

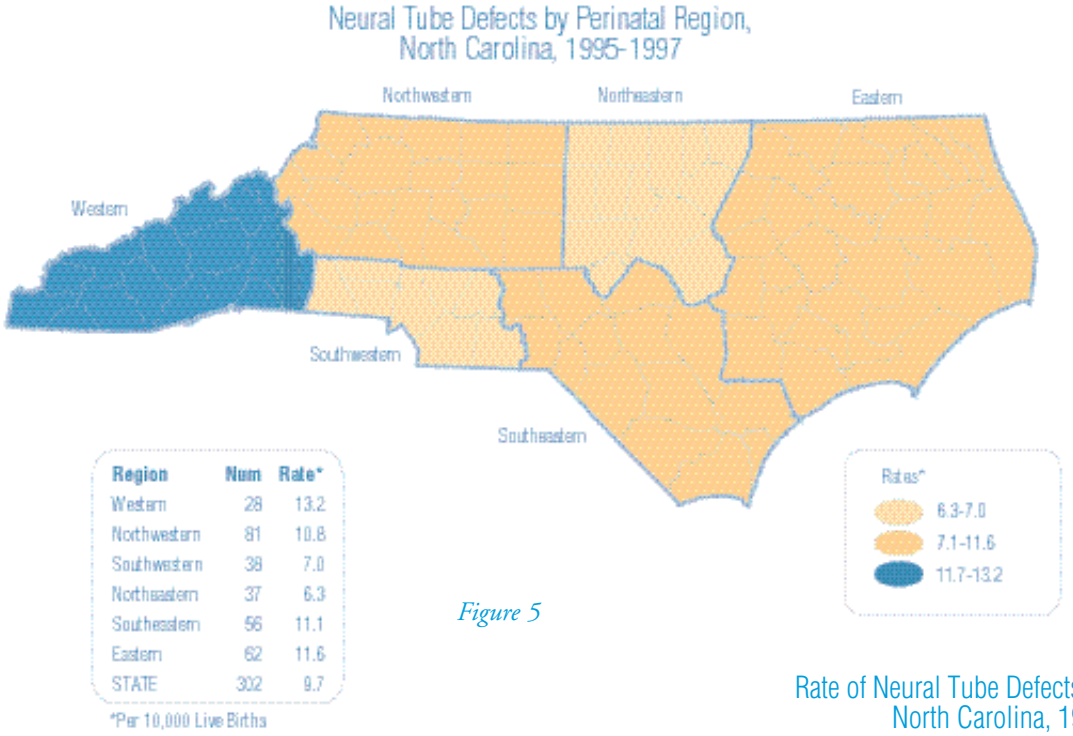


Figure 5

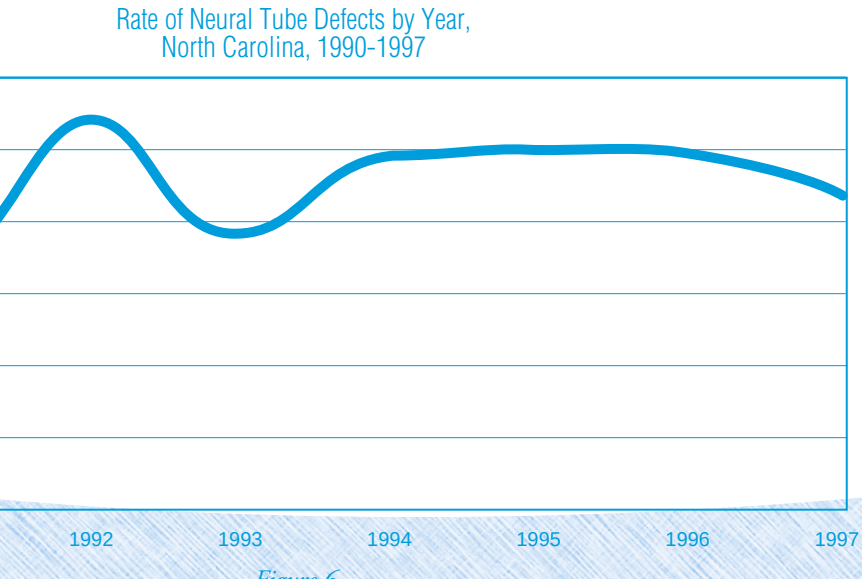


Figure 6

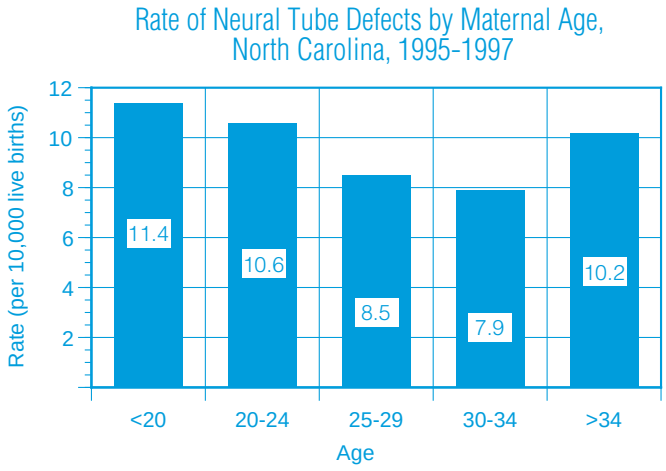


Figure 7

Orofacial Clefts

Orofacial clefts, which include cleft palate and cleft lip, occur when the structures of the mouth fail to develop properly (Figure 8). This occurs between the fourth and eighth weeks of pregnancy. Cleft palate and cleft lip seem to involve somewhat different causal processes, and both may create problems with eating, drinking, hearing, and/or speech. Individuals with cleft palate and/or cleft lip are often treated with surgery, orthodontia, and speech therapy.

Orofacial clefts can occur alone (isolated) or with other birth defects (syndromic/associated). As shown in Figure 9, nearly 56 percent of infants with cleft palate alone have one or more additional birth defects. About 32 percent of infants with cleft lip, with or without cleft palate, have additional birth defects.

Figure 8

Frequency of Syndromic/Associated Birth Defects Among Infants with Orofacial Clefts, North Carolina, 1995-1997

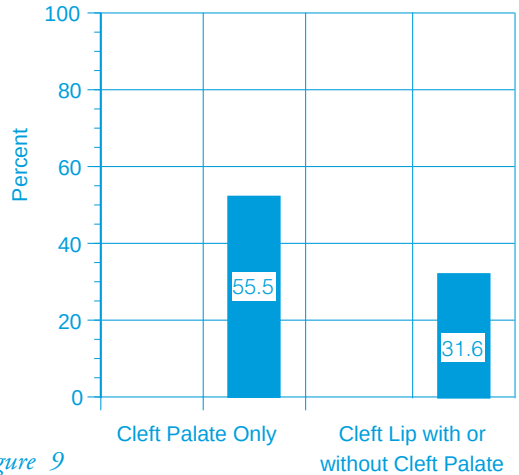
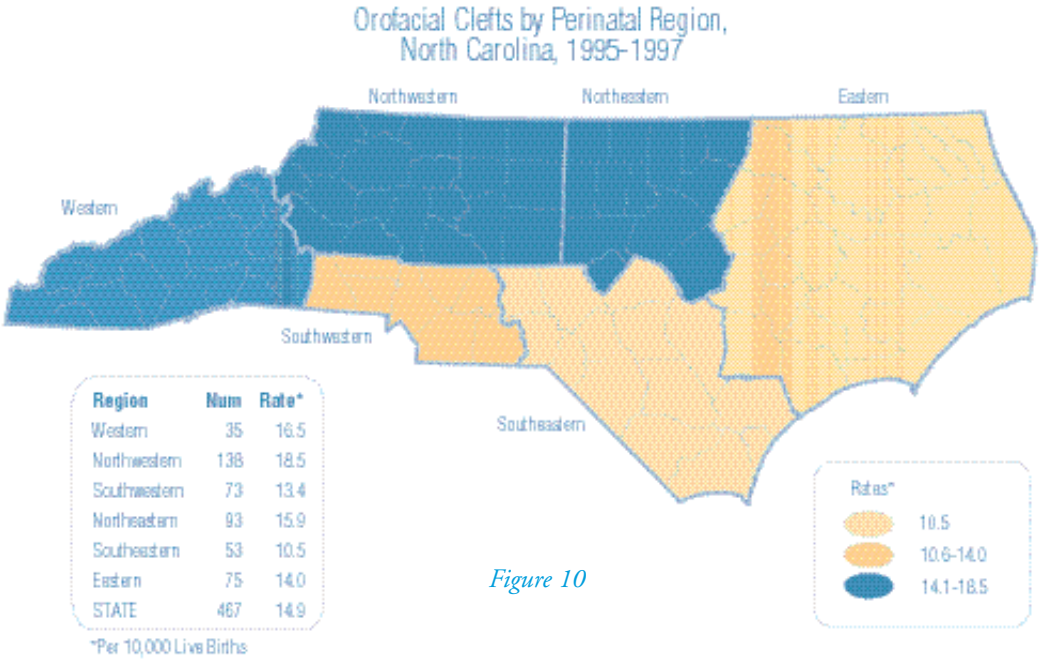


Figure 9

Nearly 130 cases of orofacial clefts occur each year among infants born in North Carolina. Approximately 43 percent of orofacial clefts involve clefts of the palate only, while 57 percent involve cleft lip with or without cleft palate. Cleft lip with or without cleft palate is more common in males and among Whites in the state. An increased prevalence is noted in the northeastern, northwestern, and western perinatal regions of the state (Figure 10). The rate of orofacial clefts increased between 1990-96 (Figure 11).

Some studies suggest that a woman who smokes during pregnancy may have an increased risk for delivering an infant with an orofacial cleft.[7-8] In addition, the intake of folic acid (400 micrograms/day) before and during pregnancy may prevent some orofacial clefts from occurring.



Region	Num	Rate*
Western	35	16.5
Northwestern	138	18.5
Southwestern	73	13.4
Northeastern	93	15.9
Southeastern	53	10.5
Eastern	75	14.0
STATE	467	14.9

*Per 10,000 Live Births

Figure 10

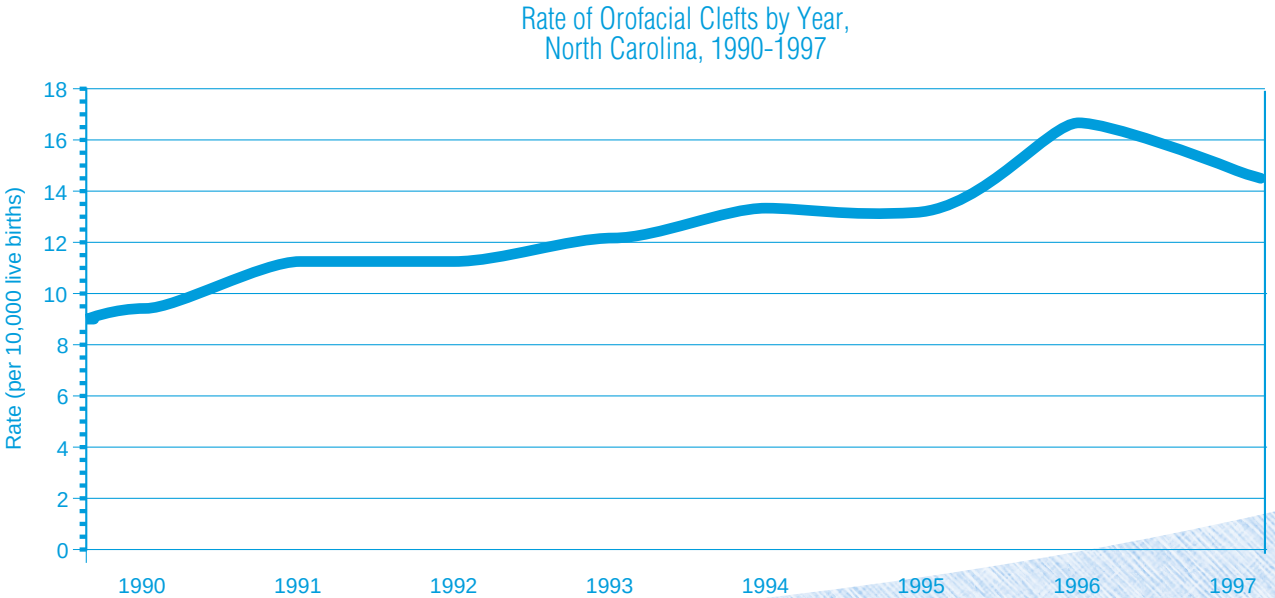
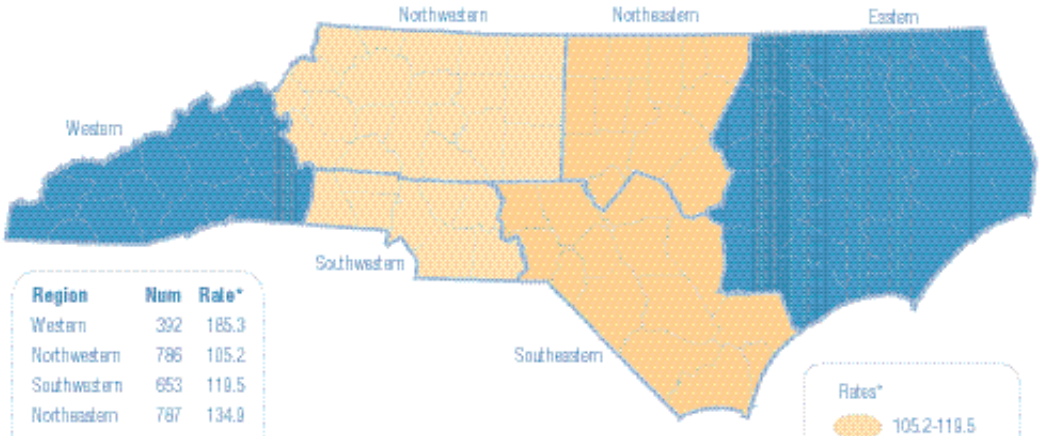


Figure 11

Cardiovascular Defects

Cardiovascular defects include defects of the heart and circulatory system. There are numerous types of cardiovascular defects, which may be caused by many different factors. Cardiovascular defects are often associated with other birth defects and chromosomal disorders. Treatment of cardiovascular defects depends on the particular defect and its severity. Mild cardiovascular defects may resolve on their own without medical intervention, while the serious defects often require surgery.

Cardiovascular Defects by Perinatal Region, North Carolina, 1995-1997



Region	Num	Rate*
Western	392	185.3
Northwestern	786	105.2
Southwestern	653	119.5
Northeastern	787	134.9
Southeastern	754	149.6
Eastern	872	162.5
STATE	4,244	135.6

*Per 10,000 Live Births

Figure 12

Overall, about 1000 infants are born with cardiovascular defects in North Carolina each year, making it the most commonly occurring birth defect in the state as well as the nation. These conditions occur at higher rates in the western and eastern perinatal regions of North Carolina (Figure 12). The prevalence of cardiovascular defects rose sharply after 1993 and leveled off after 1995 (Figure 13). Most of the increase was due to an increase in the number of diagnosed cases of atrial septal defect (ASD), ventricular septal defect (VSD), and anomalies of the heart valves, which together account for almost one-half of all cardiovascular defects. (Figure 14). This trend may be attributed to the growing use of more sensitive procedures (such as echocardiography) to diagnose infants with congenital heart disease.

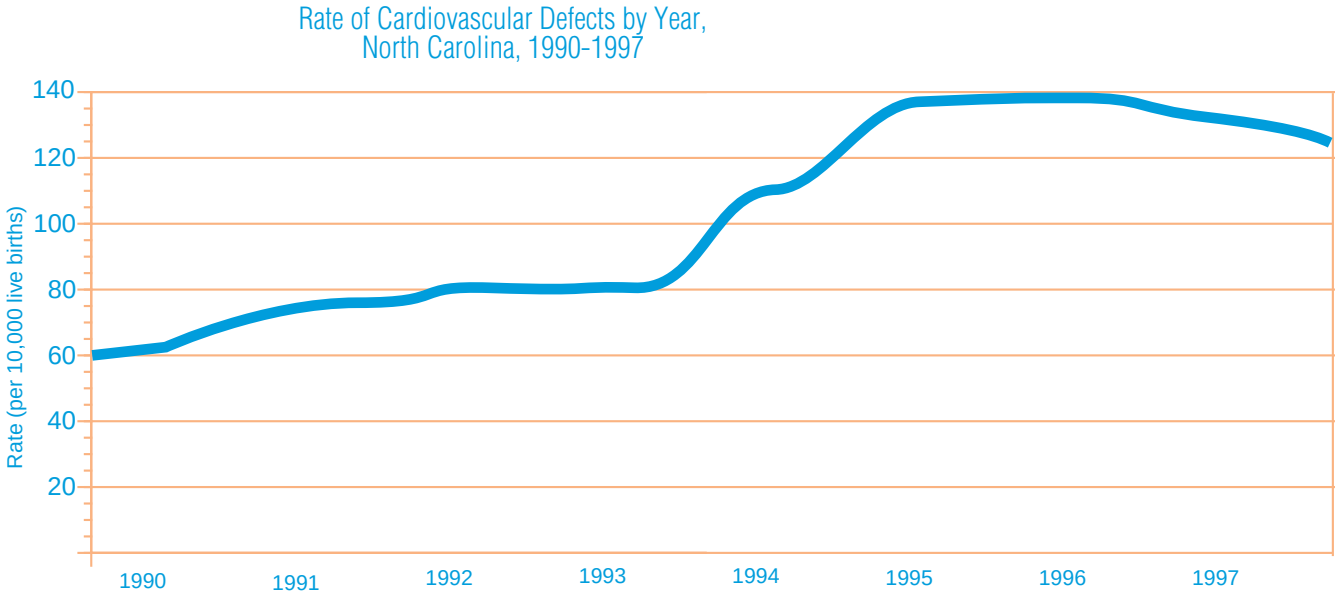


Figure 13

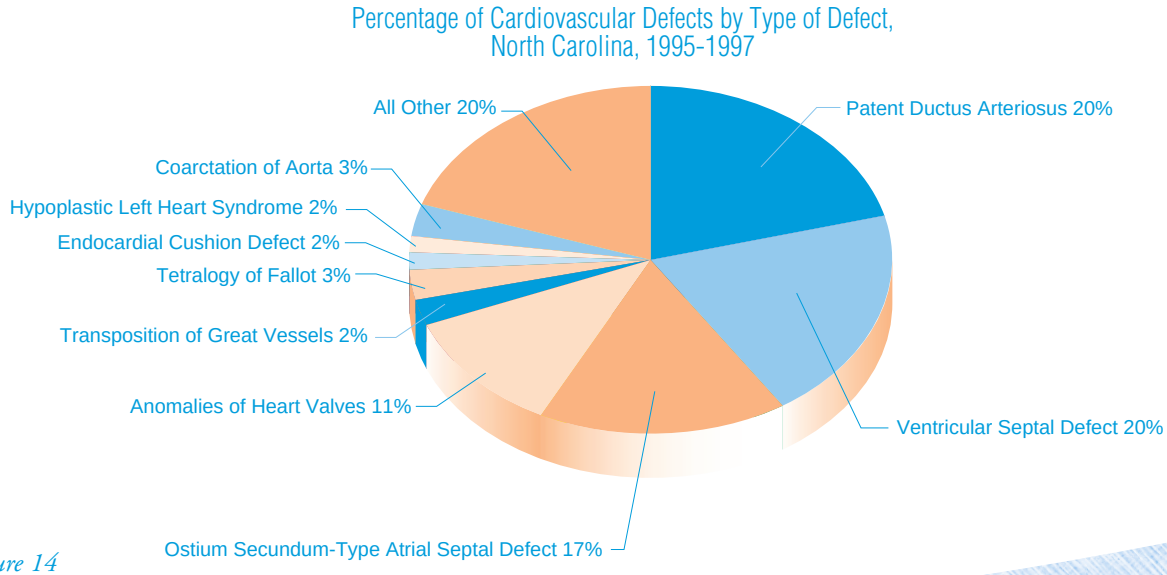


Figure 14

Chromosomal Disorders

Chromosomes are the inherited, microscopic structures that house our hereditary information in the form of genes. Humans normally have 23 pairs of chromosomes (46 total) in each of their body cells (Figure 15). Chromosomal disorders typically arise from an abnormal number of chromosomes or from certain defects in specific segments of the chromosomes. These conditions can occur spontaneously or can be inherited. Some of the more frequently occurring disorders in this group include trisomy 21 (Down syndrome), trisomy 13 (Patau syndrome), Klinefelter syndrome, and Turner syndrome. Chromosomal disorders can cause physical birth defects, mental retardation, fetal and infant death, and shortened life expectancy.

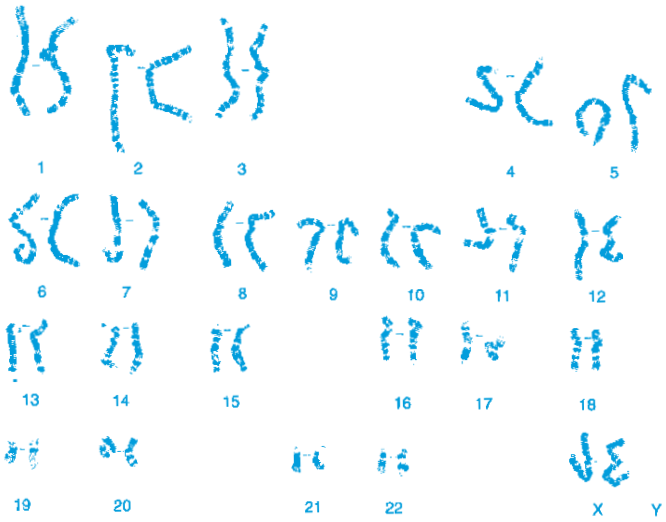


Figure 15

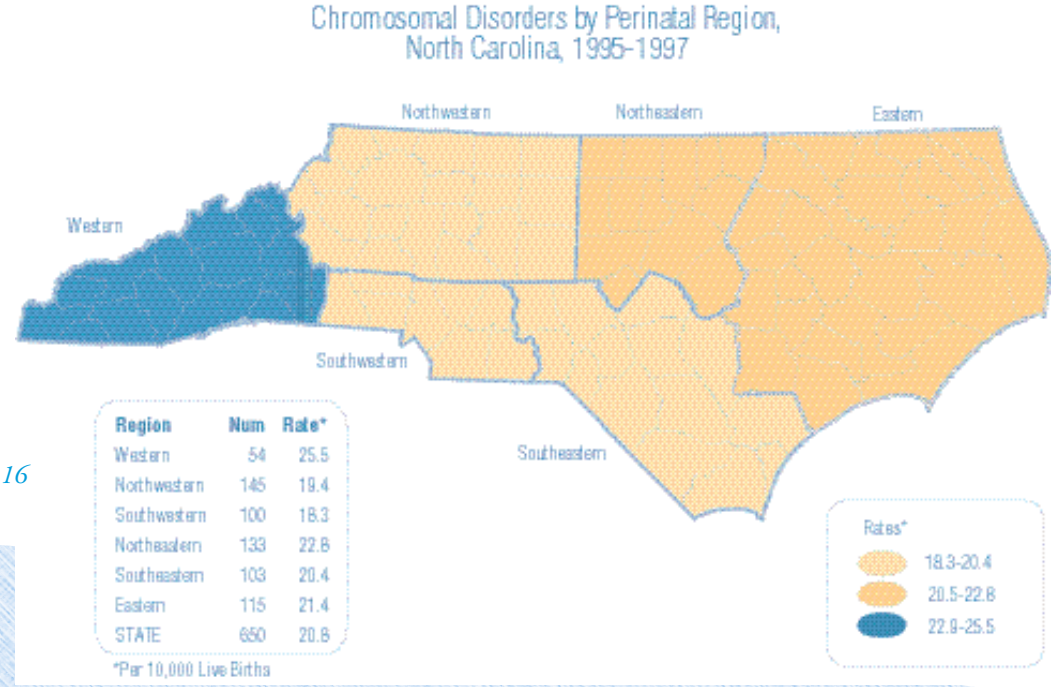


Figure 16

Chromosomal disorders occur in approximately 180 infants each year in North Carolina, with a slightly higher rate in the western perinatal region (Figure 16). During 1990-93, the prevalence of chromosomal disorders remained fairly constant; however, after 1993, the rate began to increase (Figure 17). In addition, women over age 34 are at a much higher risk for having pregnancies affected by chromosomal disorders than younger women (Figure 18). The reason for the increased risk among older women is not well understood.

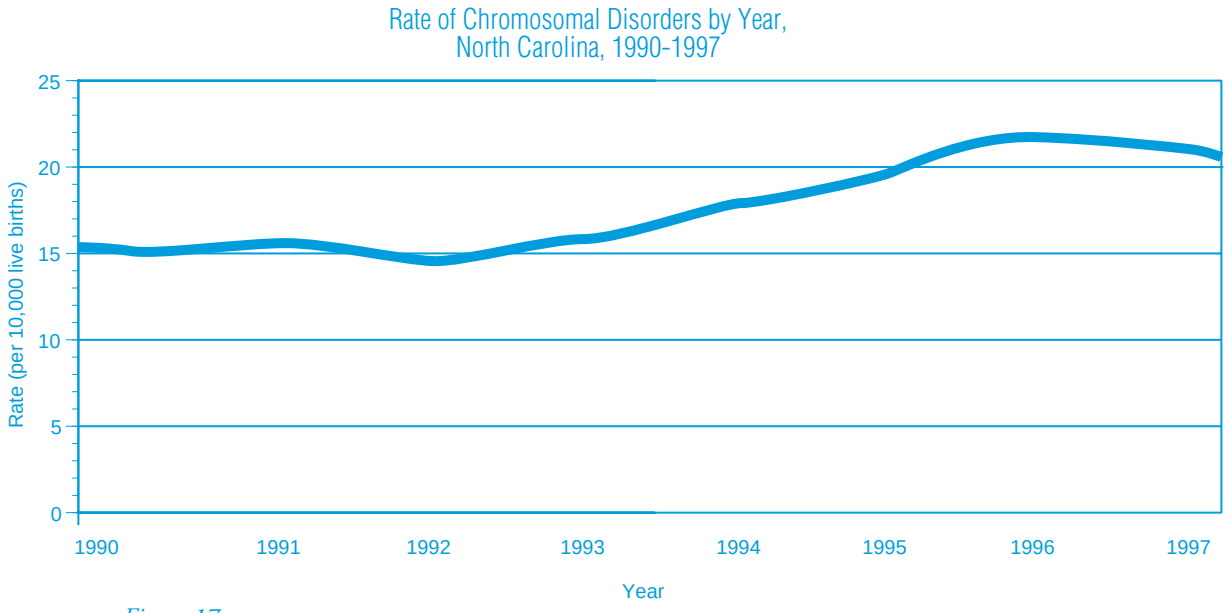


Figure 17

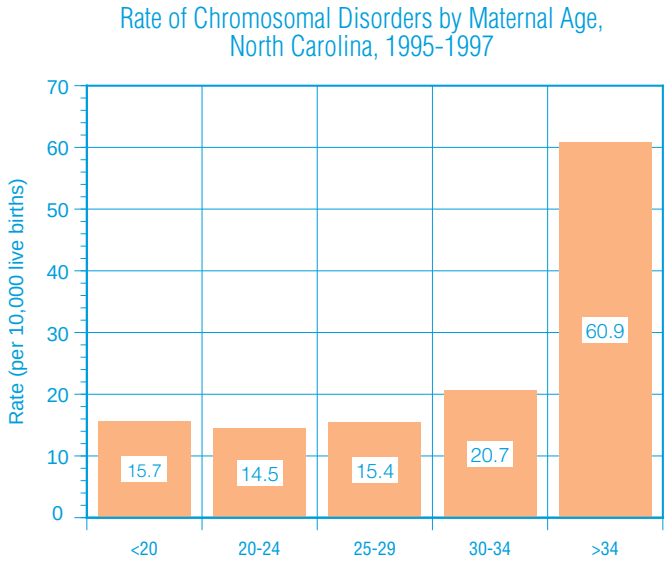


Figure 18

During pregnancy, most couples are eager to learn as much information as possible about the health of their developing baby. In the past 20-30 years, several techniques have been developed that allow parents to obtain this information. It is important to note that these testing options are handled **non-directively**, allowing parents to be in charge of the decisions made regarding their pregnancy and unborn child.

Prenatal Diagnosis

Maternal Serum Alpha-Fetoprotein (MSAFP) Screening

MSAFP Screening measures the amount of Alpha-Fetoprotein (AFP) and other substances present in the mother's blood. These results can be studied to determine if a pregnancy is at a **higher or lower risk** for the following conditions:

- Neural tube defects
- Trisomy 21 (Down syndrome)
- Trisomy 18 (Edward syndrome)
- Abdominal wall defects

This screening method cannot tell a parent whether or not the baby actually has one of these conditions, only if the pregnancy is at a **higher or lower risk** for one of these conditions.

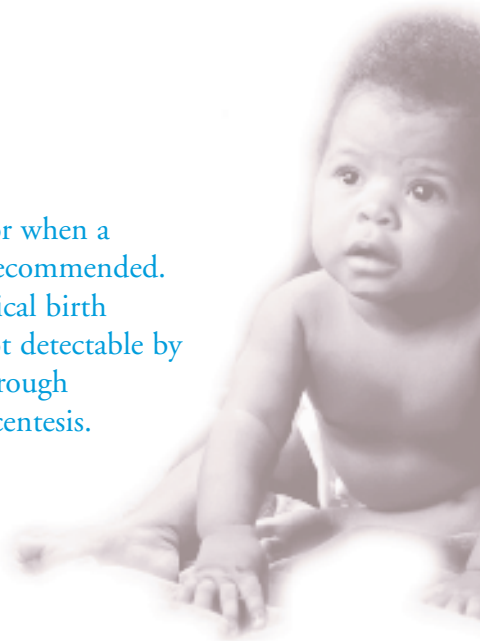
If the screen indicates an increased risk, the woman will be offered further testing. Usually this involves a detailed, or 'Level 2', ultrasound and genetic counseling. The parents then decide whether they want to pursue diagnostic testing, such as amniocentesis, to confirm that the baby has one of these conditions.

Ultrasound

Ultrasound is a helpful tool used to visualize a baby during pregnancy. Ultrasound uses sound waves that reflect off the baby's body to reveal a 'picture' of the baby. Ultrasound can:

- Estimate gestational age
- Determine if the baby is developing properly
- Determine if one or more babies are present
- Detect certain birth defects

When there is suspicion of an abnormality on a general ultrasound, or when a woman's MSAFP screen is abnormal, a 'Level 2' ultrasound may be recommended. A 'Level 2' ultrasound is up to 90% effective at detecting major physical birth defects in a developing baby. However, chromosomal disorders are not detectable by either a general or a 'Level 2' ultrasound and need to be identified through diagnostic testing, such as chorionic villus sampling (CVS) or amniocentesis.



Amniocentesis

Amniocentesis is a form of diagnostic testing that:

- Studies cells in the amniotic fluid for chromosomal disorders
- Can usually confirm or rule out problems associated with elevated MSAFP
- Has a 1/200 (0.5 %) potential risk of miscarriage
- Produces highly accurate results
- Is typically performed during 15th-18th weeks of pregnancy

Chorionic Villus Sampling (CVS)

CVS is a form of diagnostic testing that:

- Studies cells in the growing placenta (chorionic villi) for chromosomal disorders
- Cannot detect problems associated with elevated MSAFP
- Has a 1/100 (1%) potential risk of miscarriage
- Produces highly accurate results
- Is performed early in pregnancy (10th-12th weeks)

Whether or not to have diagnostic testing is always a decision that must be made **by the parents**, due to the risks and ethical concerns associated with these techniques.

Genetic Services

In recent years, the field of medical genetics has grown at an extremely rapid pace. Advancements in the field have created an increasing need for health professionals trained to explain genetic information to families. The North Carolina Genetic Health Care Program, part of the Division of Public Health, provides comprehensive genetic services for any infant, child, adult, or pregnant woman suspected of having a genetic condition.

Genetics consultations, or evaluations, may be helpful for individuals who have:

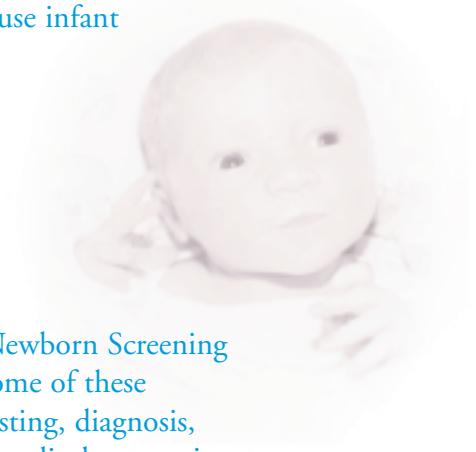
- A genetic disorder (e.g., trisomy 21, Huntington disease)
- A family history of birth defects
- Mental retardation or a family history of mental retardation
- A race or ethnic background with a higher incidence of certain disorders (e.g., Tay Sachs disease, sickle cell disease)
- A history of cancer, heart disease, or certain other diseases
- Maternal age during pregnancy of 34 or older
- An abnormal ultrasound or MSAFP screening during pregnancy

During a genetic evaluation, a genetic counselor and/or clinical geneticist may:

- Gather information regarding the reason for referral
- Review the medical, family, and pregnancy histories
- Review medical records
- Describe the diagnosis under consideration and issues regarding the diagnosis
- Order testing for a disorder
- Interpret the results of physical examinations and tests
- Communicate the information to the family
- Support the family and help with coping skills
- Follow up and maintain on-going communication with the family

Newborn Screening

Under the Newborn Screening Program, the State Laboratory of Public Health screens all newborns born in North Carolina by using a heel-stick blood sample. With early diagnosis and medical treatment, serious illness in affected infants can often be prevented. The State of North Carolina currently screens for the following metabolic disorders which, if left undetected or untreated, can cause infant mortality, morbidity, and/or developmental disabilities:



- Phenylketonuria (PKU)
- Congenital Hypothyroidism (CH)
- Galactosemia
- Congenital Adrenal Hyperplasia (CAH)
- Hemoglobinopathies (Sickle Cell Disease)

Timely follow-up is provided by the State Genetic Health Care Newborn Screening Program on all infants with suspicious laboratory results. Since some of these metabolic disorders can affect a child very early in life, prompt testing, diagnosis, and treatment is crucial. Treatment is coordinated by the major medical centers in consultation with the infant's local physician.

Additionally, the North Carolina State Laboratory of Public Health has recently initiated tandem mass spectrometry (TMS) screening to detect other metabolic disorders. This sophisticated addition is helping to make North Carolina a leader in the provision of newborn screening services.

Prevention Methods

By taking precautions before and during pregnancy, a woman can reduce her risk of delivering a baby born with a birth defect or other adverse outcome. A woman should start planning for the health of her baby **before** she becomes pregnant. During the first three to eight weeks after conception, many of the baby's vital organs and systems are being formed. By the time most women know they are pregnant, their baby's development is well underway, and some birth defects may have already occurred. While there is never a guarantee for a healthy baby, the following list of preventive measures can increase a woman's chance of having a healthy pregnancy and a healthy baby.

- **Talk with your health care provider**
  Prior to pregnancy, it is a good idea to talk with a health care professional. During this time, a health care provider can identify any health risks a woman may be facing and work with her to address them before she becomes pregnant. It is important to have conditions such as diabetes, epilepsy, and high blood pressure under control **before** becoming pregnant. If there is a history of an inherited or genetic disorder, consultation with a genetic counselor may be recommended.
- **Consume folic acid**
  Several studies have shown that women who take a daily multivitamin with 400 micrograms of folic acid **before** and during pregnancy decrease the risk that their baby will be born with a neural tube defect by up to 70 percent. Consuming folic acid may also prevent other birth defects, such as cleft lip/cleft palate and some congenital heart defects. For adults, folic acid may offer protection from illnesses such as heart disease and colon cancer.
- **Eat a healthy diet**
  Women and their developing babies can benefit from good nutritional habits before and during pregnancy. It is highly recommended that all women eat a well-balanced and varied diet and take a multivitamin every day.
- **Exercise regularly**
  Regular exercise can benefit a woman's body by increasing overall strength and by creating a healthy environment in which her baby can develop. Talk with a health care provider to determine an appropriate exercise level.
- **Achieve an ideal weight**
  The preconceptional period is an excellent time to achieve an ideal weight. Women who start their pregnancies underweight or overweight may have problems. If a woman is overweight at the time of conception, she is more

likely to develop high blood pressure and diabetes during pregnancy. If a woman is underweight, she is more likely to deliver a low birthweight baby.

- **Avoid smoking**
  Women should avoid smoking during pregnancy, as well as limiting exposure to secondhand smoke. Smoking during pregnancy is associated with an increased risk of miscarriage and stillbirth, SIDS (sudden infant death syndrome), and low birthweight. In addition, children exposed to smoke may have behavioral problems, learning difficulties, and an increased risk for respiratory problems and asthma.
- **Avoid alcohol**
  The harmful effects of alcohol on an unborn baby's growth and development are numerous. Fetal alcohol syndrome (FAS) is the most severe, creating physical, mental, and behavioral problems in infants. Alcohol consumption during pregnancy is the leading cause of **preventable** mental retardation among infants.
- **Avoid illicit drugs**
  Research has shown that in-utero exposure to illicit drugs can cause direct toxic effects on a developing baby, as well as create fetal and maternal dependency. The baby may experience withdrawal prenatally when drugs are withdrawn from a dependent mother, or after delivery.
- **Limit exposure to environmental hazards**
  Pregnant women should minimize exposure to toxic substances and chemicals. They should also avoid eating undercooked meat and handling cat litter, as these activities may lead to an infection known as toxoplasmosis, which can seriously harm a developing fetus. There are a few foods, including certain types of fish, some soft cheeses, and ready-to-eat meats, which may also pose a risk during pregnancy.
- **Discuss medications**
  All medications, prescription or over-the-counter, a woman may be taking should be discussed with a pharmacist or health care provider, as these may not be appropriate to use during pregnancy.
- **Check immunizations**
  It is important for a woman to check her immunization history before pregnancy. If she is not immune to chickenpox and rubella, or has not received her hepatitis B series, she should talk with her health care provider about her risks.

Women with questions about any of the above should talk with their health care provider. They can also call the National March of Dimes Resource Center at 1-888-MODIMES.

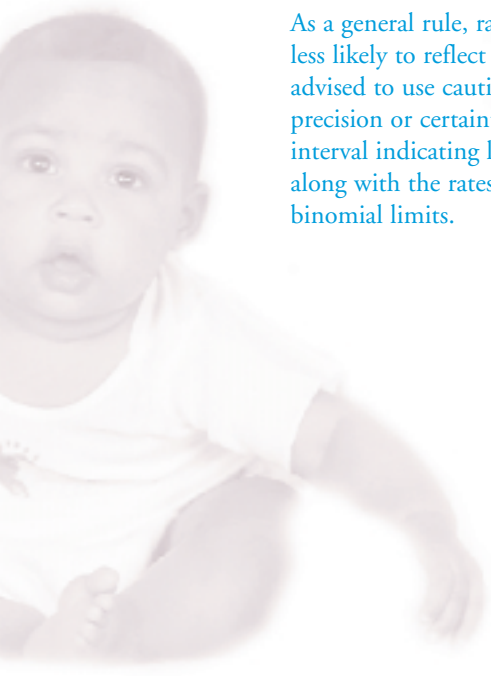
Technical Notes

The North Carolina Birth Defects Monitoring Program (NCBDMP) operates under the statutory authority (G.S. 130A-131.17) of the State Center for Health Statistics, North Carolina Department of Health and Human Services. The purpose of the NCBDMP is to compile, tabulate, and publish information related to the incidence and prevention of birth defects. All identifying information collected by the NCBDMP is considered confidential by state law.

The NCBDMP collects information on all infants in North Carolina who are born with birth defects. The data are maintained in the program's central registry. In order to be included in the registry, the infant must have been born to a resident of North Carolina and be diagnosed with one or more birth defects within the first year of life. Residency at the time of birth is verified by matching case records to state vital statistics files. This linkage also provides a means of unduplicating cases to allow calculation of rates. The birth defects covered generally include those within the range of ICD-9-CM codes 740.0-759.9, excluding certain minor anomalies. The registry includes all live-born infants regardless of gestational age, and all fetal deaths of 20 weeks gestation or more. The program also monitors neural tube defects diagnosed in fetal deaths prior to 20 weeks gestation and in pregnancy terminations; however, these cases are not included in the present report. The NCBDMP uses two main approaches to ascertain infants with birth defects. One approach involves linkage of existing health databases, including vital records, hospital discharge data, and Medicaid paid claims files to identify reported diagnoses of birth defects. The second approach, which was initiated in 1997, involves the use of trained staff who systematically review and abstract medical records at the state's 12 tertiary hospitals. This second approach presently focuses on a more limited subset of birth defects which are particularly difficult to reliably ascertain from the existing data systems.

Unless otherwise indicated, all data in this report are for the three-year period 1995-97. Three-year rates rather than single-year rates are used to improve the statistical stability of the data. The NCBDMP has had statewide, population-based coverage since 1989; however, in 1994 patient-level hospital discharge data were not available and, as a result, the registry did not produce data for that year. For the trend graphs in this report, data for 1994 were estimated based on the average rates for 1992-93 and 1995-96.

As a general rule, rates based on fewer than 20 observed cases tend to be unreliable; that is, they are less likely to reflect the true rate than are those based on a larger number of cases. The reader is advised to use caution when interpreting rates based on small numbers of events. The degree of precision or certainty of a rate is also reflected by the width of the confidence interval, with a wider interval indicating less precision. The table in the Appendix provides 95 percent confidence intervals along with the rates to facilitate interpretation. These confidence intervals are based on the exact binomial limits.



Appendix

Number of Cases and Rates (per 10,000 births) for Selected Birth Defects, North Carolina, 1997 and 1995-97

	1997		1995 - 1997			
					95% Confidence Limits*	
	Number	Rate	Number	Rate	Lower	Upper
Central Nervous System						
Anencephalus	28	2.6	75	2.4	1.9	3.0
Spina Bifida without Anencephalus	57	5.3	185	5.9	5.1	6.8
Encephalocele	14	1.3	50	1.6	1.2	2.1
Microcephalus	64	6.0	172	5.5	4.7	6.4
Hydrocephalus without Spina Bifida	131	12.2	320	10.2	9.1	11.4
Eye						
Anophthalmos/Microphthalmos	15	1.4	43	1.4	1.0	1.9
Congenital Cataract/Lens Abnormalities	11	1.0	40	1.3	0.9	1.7
Cardiovascular						
Common Truncus	8	0.7	22	0.7	0.4	1.1
Transposition of Great Arteries	41	3.8	137	4.4	3.6	5.2
Tetralogy of Fallot	52	4.9	155	5.0	4.2	5.8
Ventricular Septal Defect	419	39.2	1121	35.8	33.8	38.0
Atrial Septal Defect	339	31.7	944	30.2	28.3	32.2
Endocardial Cushion Defect	34	3.2	88	2.8	2.3	3.5
Pulmonary Valve Stenosis/Atresia	158	14.8	403	12.9	11.7	14.2
Tricuspid Valve Stenosis/Atresia	13	1.2	27	0.9	0.6	1.3
Ebstein's Anomaly	8	0.7	13	0.4	0.2	0.7
Aortic Valve Stenosis/Atresia	21	2.0	53	1.7	1.3	2.2
Hypoplastic Left Heart Syndrome	29	2.7	86	2.7	2.2	3.4
Patent Ductus Arteriosus	381	35.6	1179	37.7	35.6	40.0
Coarctation of Aorta	65	6.1	169	5.4	4.6	6.3
Pulmonary Artery Anomaly	124	11.6	304	9.7	8.7	10.9
Respiratory						
Choanal Atresia	21	2.0	58	1.9	1.4	2.4
Lung Agenesis/Hypoplasia	28	2.6	71	2.3	1.8	2.9

Number of Cases and Rates (per 10,000 births) for Selected Birth Defects, North Carolina, 1997 and 1995-97

	1997		1995 - 1997			
					95% Confidence Limits*	
	Number	Rate	Number	Rate	Lower	Upper
Orofacial and Gastrointestinal						
Cleft Palate without Cleft Lip	67	6.3	212	6.8	5.9	7.8
Cleft Lip with or without Cleft Palate	92	8.6	285	9.1	8.1	10.2
Tracheoesophageal Fistula/Atresia	49	4.6	122	3.9	3.2	4.7
Rectal and Intestinal Stenosis/Atresia	57	5.3	168	5.4	4.6	6.2
Hirschsprungs Disease	41	3.8	84	2.7	2.1	3.3
Genitourinary						
Hypospadias/Epispadias	542	50.7	1355	43.3	41.0	45.7
Renal Agenesis/Hypoplasia	43	4.0	126	4.0	3.4	4.8
Obstructive Genitourinary Defects	185	17.3	503	16.1	14.7	17.5
Bladder Exstrophy	4	0.4	14	0.4	0.2	0.8
Musculoskeletal						
Congenital Hip Dislocation	160	15.0	533	17.0	15.6	18.5
Club Foot without CNS Defect	75	7.0	256	8.2	7.2	9.2
Reduction Defect of Upper Limb	28	2.6	91	2.9	2.3	3.6
Reduction Defect of Lower Limb	19	1.8	45	1.4	1.0	1.9
Diaphragmatic Hernia	33	3.1	116	3.7	3.1	4.4
Chromosomal						
Trisomy 21 (Down Syndrome)	129	12.1	371	11.9	10.7	13.1
Trisomy 13	16	1.5	40	1.3	0.9	1.7
Trisomy 18	25	2.3	81	2.6	2.1	3.2

*Exact binomial confidence limits

Resources

State Center for Health Statistics
www.schs.state.nc.us/SCHS/
919-733-4728

March of Dimes
www.modimes.org
1-888-MODIMES

Family Support Network of North Carolina
www.med.unc.edu/commedu/familysu
1-800-852-0042

North Carolina Folic Acid Council
1-877-237-0085

North Carolina Family Health Resource Line
1-800-367-2229

Spina Bifida Association of North Carolina
www.sbanc.org
1-800-84-SBANC

The Cleft Palate Foundation
1-800-24-CLEFT

The Children's Health Network
(Congenital Heart Disease Information and Resources)
www.tchin.org
215-493-3068

National Down Syndrome Society
www.ndss.org
1-800-221-4602

National Birth Defects Prevention Network
www.nbdpn.org

Centers for Disease Control and Prevention
www.cdc.gov
1-800-311-3435

North Carolina Division of Public Health
www.dhhs.state.nc.us/dph/
919-733-3816

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Cover poem, excerpt from "Where Do You Come From, Baby Dear?" by George MacDonald (1871)

The University of North Carolina Birth Defects Center

RESEARCH PREVENTION TREATMENT

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